



## The power of storytelling:

### collecting & sharing our mission moments

Step One: Identify people with compelling stories and invite them to share them with the community.

Finding sources:

- Run a report in Donor Drive to identify those who have updated their personal fundraising page
- New team captains or your veterans who come back year after year
- Newly diagnosed families who have connected with the chapter
- Active board or committee members

**Tip: Trying highlighting someone whose story you haven't told before. You want to try to capture a diversity of stories and experiences.**

Step Two: Contact your potential storyteller and ask them if they would like to share their story. Be very clear about how you will be using this story and how public it will be. For example: *"I would like to interview you for a story in our chapter newsletter about our walk. It will be going out to the community as well as posted on our Facebook page."*

Step Two: Set up a time to get to know your storyteller. Interviews should take between 10-30 minutes. Ask more questions than you think you can use.

Possible questions:

1. How are you/your family affected by bleeding disorders?
2. What did it feel like when you first heard the doctor say, "Your child has hemophilia/VWD?"
3. What did you do when you first got that diagnosis?
4. How did you first discover our chapter?
5. What was the first chapter event that you went to? What did you learn? How did it make you feel?
6. *Ask directly about a service/event that you provide if you know a person attends.* Example: "Does Chris go to camp? How does he/she like it?" "You come to our men's group. What do you like best about that?"
7. How long have you been participating in our walk?
8. Who is the inspiration for your Walk team?
9. What does it mean to you to have the community come together for a bleeding disorders walk?
10. Why do you think it's important to raise money for the chapter through the Walk?
11. What is your fundraising goal?
12. What's the one thing you wish people who aren't in the community knew about bleeding disorders?
13. Aside from a cure – because we all want that – what is the one thing you wish for the bleeding disorders community?
14. Is there anything you would like to talk about that I haven't asked about?
15. Do you have some photos that I can use to help tell this story?



Final questions: How they would like to be identified – full name? Diagnosis? Family members names?

**Tips: Plan on recording the interview. You can either use one of those little digital voice recorders, or the voice recorder on your phone. If you are conducting the interview over the phone, be sure to inform the interviewee that you are recording the call. (“If it’s all right with you, I’m going to record this so I can be sure to capture your words accurately.”)**

Share the story: **Sample story 1**

Warriors for the Cause

Wanda Walker is a busy mom with two young boys with hemophilia A. William, 6, and Wylie, 10, are active boys who are constantly on the go – and the inspiration for her walk team “W’s Warriors.”

“When Wylie was first diagnosed, I really felt lost,” Wanda said. “I didn’t know much about hemophilia and I didn’t know what it meant for someone to have it.” She was referred by Local HTC to Awesome Chapter, and where she found a community she didn’t know existed.

“At my first education day, it was just a relief to meet other moms who could understand what I was going through,” she said. Awesome Chapter’s Education Days are held once a year, feature practical education sessions, and give families a chance to connect and get to know each other. This support is important to families who are new to bleeding disorders. “Seeing other kids with bleeding disorders running around being regular kids gave me hope,” she said. “I knew we’d be able to handle this.”

The Walkers have participated Our Chapter’s Walk since 2014 with her “W’s Warriors” team. Last year, they raised \$1,145 and this year have set a goal of \$2,000. “We want to give back to the chapter that has given us so much,” Wanda said.

There is still time to register for Our Chapters Unite for Bleeding Disorders Walk! Go to [UniteforBleedingDisorders.org](http://UniteforBleedingDisorders.org) to find out how to get involved.

**Facebook post 1**

“We want to give back to the chapter that has given us so much.” Meet Wanda, Wylie and William, the warriors of our Unite for Bleeding Disorders Walk.

**Facebook post 2**

Team W’s Warriors are halfway to their goal of raising \$2,000 to support Awesome Chapter! Wanda Walker shares her story.



Posts

**Unite For Bleeding Disorders**  
Published by Johnette Reed [?] · Just now · 🌐

"We want to give back to the chapter that has given us so much." Meet Wanda, Wylie and William, the warriors of our Unite for Bleeding Disorders walk.



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Team W's Warriors are halfway to their goal of raising \$2,000. Click the link to support Awesome Chapter! Wanda Walker shares her story.



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## Sample story 2

Vinnie and Violet Brand don't hesitate when they ask why they are participating in Awesome Chapter's Unite for Bleeding Disorder Walk. "Camp changed our daughter's life," Violet says.

Camp Camname, Awesome Chapter's camp for kids with bleeding disorders and their siblings, is held every year in May. Kids from across State come together to learn about how to manage their disorder, but also to swim, hike, horseback ride, go on nature walks, fish – but most importantly, meet other kids with bleeding disorders.

"Before she went to camp, our daughter had never met anyone with von Willebrand disease before," said Vinnie. "She was having a hard time with it." Their daughter was diagnosed with VWD type 3 severe when she was nine years old. A Google search led them to the chapter.

"I called them to ask if they had any information about VWD, which they did, and also they invited us to their holiday party," Violet said. "That's where we learned about the camp."

The Brand's daughter has attended the camp for three years. The Brands said meeting other girls with a bleeding disorder made her more accepting of her condition, and comfortable talking about it. "We're really proud of how she's handling it now," said Vinnie.

The Brands are trying to raise \$500 with their team, Brand's Winners. Their team is made up of family and friends who are all supporting their daughter. "So many people don't know anything about VWD," said Violet. "We're walking to help raise that awareness."



**Facebook post 2**

Meet Team Brand, who are walking to raise awareness of von Willebrand disease.

“Camp changed our daughter’s life.” Team Brand’s Winners are inspired to walk for Camp CampName.



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"Camp changed our daughter's life." Support Team Cool Clots today. Your support helps girls like Olivia attend camp.



[uniteforbleedingdisorders.org](http://uniteforbleedingdisorders.org)  
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"Camp changed our daughter's life." Team Brand's Winners are inspired to walk for Camp CampName.



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Your character:

Who are they and how are they connected to the NEHA bleeding disorders community:

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**What has been the biggest challenge or obstacle they've faced:**

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**How has their interaction with the NEHA made a difference in tackling that challenge/obstacle:**

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**How has that support influenced how they give back:**

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**What is the call to action to those reading their story (register, donate, advocate):**

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 **Unite For Bleeding Disorders** ...  
Published by Tracy Stoychoff Earll [?] · March 6 · 🌐

Mark Castenson and his wife didn't know they had a history of hemophilia in their family. So you can imagine their shock when they found out a few weeks after their son Asher was born that he had severe hemophilia. But because of the support of their local chapter in Iowa, Asher is now an extremely active 10yo boy they couldn't be more proud of.

They are proud to walk in their local UNITE Walk to show their appreciation and support for all their chapter has done for them. Join Mark and Asher and register today at [www.uniteforbleedingdisorders.org](http://www.uniteforbleedingdisorders.org) Your local chapter needs your support to continue to provide families like the Casterson's the support they need.



 **Unite For Bleeding Disorders** ...  
Published by Katie Cooper [?] · March 28 at 11:31am · 🌐

"Our son, George, was diagnosed with spontaneous severe hemophilia over 2 years ago at 5 months old. Raising funds for the Colorado Chapter, National Hemophilia Foundation who provides so much for us and everyone affected is the least we can do to give back. Join us by participating in a walk near you, <https://uniteforbleedingdisorders.org>" - Stephanie Weilert

